

The First Step

LOCAL ORGANIZATIONS SEE **NATIONAL AUTISM AWARENESS MONTH** AS A MEANS TO BUILD A MORE ACCEPTING, INCLUSIVE WORLD.

By Madeleine Maccar

April's National Autism Awareness Month isn't just about 30 days of increased visibility: Advocates emphasize that one month of proactive awareness helps foster increasing inclusion, acceptance and understanding of a group who may share one label but present it as individually and nuanced as their own personalities.

After all, advocates often remark that if you've met one person with autism, then you've met one person with autism.

Properly called autism spectrum disorder, the diagnosis' formal name underscores how autism manifests itself across a literal spectrum, ranging from individuals whose social or behavioral challenges don't prevent them from living independently to those with accompanying developmental disabilities or comorbidities who will require extra, lifelong care.

Dedicated awareness initiatives working toward a more inclusive, compassionate world are part of what Evesham Township's Disability & Veterans Affairs Advisory Committee has in store.

"We're able to bring awareness to systemic barriers people with autism face on a daily basis, and with that attention to those barriers, our community can work together to overcome them," says member Erin Sappio, who has a family member with a dual diagnosis of autism and a mental health disability. "Plus, the more attention we bring to the successes that individuals with autism achieve, the more the larger community recognizes the contribution people with autism can make to a community."

Formed in 2019, the committee ensures that some of the township's most vulnerable residents have a platform amplifying their voices. Different members can speak more personally to certain perspectives, either firsthand or on behalf of a loved one.

Utilizing an array of social media and Evesham Township's official channels helps members share awareness campaigns and information. One of the past year's rare silver linings according to chairperson Jeff Shapiro, is that shifting to predominantly virtual venues came with the surprise benefit of reaching more people.

"We've learned to really promote and function a lot more strategically, and being able to focus on the social media aspect is really allowing us to get our message across the entire community easily," he notes.

Local organizations are undertaking their own awareness campaigns, too. Bancroft, a nonprofit provider of developmental disability services and neurological rehabilitation headquartered in Cherry Hill, launched Real Me, a celebration of people living with autism that highlights their individuality.

"It builds a culture of community and acceptance, and also provides opportunities to help individuals with autism who need some sort of support," says Dr. Tracy Ketting, who also oversees its ABA Center of Excellence. "It is less about promoting



awareness than encouraging acceptance these days."

The Arc of New Jersey is part of a national organization working to support people with intellectual and developmental disabilities, protect their human rights, and encourage community inclusion and participation. With locations in nearly every county, each chapter customizes its services according to a community's needs: In Camden County, Arc predominantly caters to adults while its Gloucester counterpart works with children, according to JoAnn Rusnak, assistant executive director at The Arc of Camden County.

From her Berlin location, Rusnak helps adults seek housing, find work and enroll in the organization's skill-strengthening programs if they're not yet ready to apply for jobs.

"The Arc, in general, really came out of families, so we're very heavily involved with our families who felt their adult children needed more support," Rusnak says.

She says that, during her 30-year career, both individuals with developmental disabilities and the facilities that exist to help them are much more accepted by and welcomed into their communities than they were years ago, due in part to awareness efforts eliminating more and more misconceptions.

"People become more comfortable with individuals the more time they spend with them and the more they see," notes Rusnak. "There is so much information out there about what people with autism or any type of a disability can contribute to a community, how we can support them ... Sometimes, the wider community doesn't have a lot of exposure, they don't know someone with autism, so they don't understand that person's needs and what that person can bring to a job or a community."

Of course, not all people with autism can advocate for themselves through spoken communication. Kathleen Stengel of NeurAbilities Healthcare, a diagnostic and treatment facility which has locations in Voorhees and Cherry Hill, emphasizes that "not being able to verbally communicate does not mean they're not communicative."

"I've had entire conversations with individuals who were using Picture Exchange [Communication Program] on an iPad all the way through," she says, referring to one method non-verbal people use to express their autonomy and needs, which also include sign language, yes/no questions, sound boards

or email. "Everybody has something to say, everybody has amazing stories to tell, and it's our job to bring the world to them so they can tell them."

Dr. Suzanne Buchanan, the executive director of Autism New Jersey for nearly 20 years, is part of the nonprofit's 13-person team. Rather than offer direct services, the organization runs a hotline, organizes conferences, provides training and works on public policy. And to supplement its small but dedicated staff, the Autism New Jersey Ambassadors step in to help.

"We provide concerned community members—parents, siblings, teachers, anyone who's interested—with free information they can use, like teachers can find lesson plans," Buchanan says of the ambassadors. "Leading up to April, we really encourage them to develop their own awareness activity in their hometown: something like go to a local paper and write an opinion piece, or teachers and schools can do school-wide assemblies."

Buchanan adds that autism and the developmental delays once associated with it are no longer intertwined, and that metrics and numbers accordingly.

"One in 32 children meet the diagnostic criteria for autism, which is the social communication challenges and the restricted behavior, but close to one-third of them have both autism and an intellectual disability," she says. "That means approximately 70% of kids with autism in New Jersey have average or above-average IQs."

With a community comprising

such differing abilities, needs, preferences, capabilities, goals and expectations, autism can't be reduced to one-size-fits-all generalities—even when talking about the community as a whole. One example Buchanan cites is how "person-first" terminology like "people with autism" attempts to recognize an individual's identity beyond their diagnosis. But others, particularly self-advocates, prefer "autistic person" or "autistic" since they see it as a significant, essential part of them.

Rose Lynch, also a part of Evesham's advisory council, runs the township's Special Needs Adult Program (SNAP), largely inspired by ensuring her adult brother enjoyed a quality of life that kept him active and connected. When she first became his caretaker, she faced an informational overload "many, many years ago before Google" directed her to the advice and resources she wanted to act in her brother's best interest.

"I remember getting this giant packet that was not really helpful," she recalls. "If we, as a community, gather these different resources, businesses and recreation groups we can put together in one spot, they'll be able to see what's out there."

Evolving language preferences and digestible resources are two reasons why it's not just larger communities benefiting from educational resources and awareness efforts. Families who have never had to care for a person with autism might feel understandably unprepared to be thrust into the roles of their loved one's primary caretakers and fiercest advocates. While they often rise to the occasion,



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resources and classes are available to help them learn how to be what their loved one needs.

"You need to address the entire physicality of an individual person with autism," Stengel explains, noting that food sensitivity alone can present a host of health issues. "Parents are often overwhelmed early on by that wave of 'Oh, I need to do all these educational things and take care of all these medical needs.' We don't have to teach them how to be parents, but we do give them the skills to support their neurodivergent child."

Education and awareness, after all, build those foundations of understanding that lead to acceptance.

"When I first started, there was a real stigma in having a disability of any kind: The idea of celebrating someone's non-neurotypical differences wasn't there," Rusnak says. "People were never encouraged to say, 'Hey, I'm a little different and I see the world differently, so I can contribute something that you might not have thought of.' That's really become a lot more accepted."

Acceptance leads to a more inclusive world, one person and one community at a time. And while it's a big goal, it starts with one small, simple step.

"It's just about being kind," Rusnak summarizes. "When you lead with kindness, awareness and acceptance follow." ■

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